AN EVALUATION OF CALIFORNIA'S HIV CARE CONSORTIA MODEL

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AN EVALUATION OF CALIFORNIA'S HIV CARE CONSORTIA MODEL

Exploring Factors that Influence Effectiveness and Efficiency

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EXECUTIVE SUMMARY

BACKGROUND

Title II of the Ryan White Comprehensive AIDS Resources Emergency Act (RWCA) of 1990 (reauthorized in 1996) provides for the establishment and support of HIV Care Consortia. California's 34 consortia, whose members include volunteers, service providers, and people living with HIV/AIDS (PLWHA), perform the planning function pertaining to the delivery of services to PLWHA and their families. Each consortium's dual responsibility is to (1) develop a service plan that will serve the community based upon local service needs, and (2) fund the service providers who implement the service plan. The State has mandated extensive membership requirements for consortia, which includes mental health providers, substance abuse providers, agencies receiving HIV testing and early intervention funds, and the local governmental housing agencies. These expansive membership requirements bring expertise to local HIV Care Consortia and help to provide greater coordination with existing statewide and/or region-wide programs.

In light of the changing facets of the HIV epidemic, it has become essential to evaluate the original consortia model developed for a disease that has drastically changed. The California State Office of AIDS (OA), in collaboration with the Health Resources and Services Administration (HRSA), has conducted a study of California's Title II RWCA HIV Care Consortia model. The study evaluates the efficiency and effectiveness of California's RWCA consortia in assessing needs, setting priorities, and delivering services to individuals and families with HIV disease.

RESEARCH DESIGN AND DATA ANALYSES

The consortia model's ability to address the special care and service needs of PLWHA and their families is of primary interest to both OA and HRSA. The research design includes an examination of the consortia's internal processes as a measurement of consortia **efficiency** and percent of clients' needs met as a measurement of consortia **effectiveness**.

To measure the concepts of efficiency and effectiveness, information from both RWCA consortia members and clients was required. Two survey instruments were developed to collect information from these two overlapping populations. A call-in, computer assisted, telephone interview system was utilized for collecting survey responses. The OA distributed flyers at HIV Care Consortia and Planning Council meetings notifying members, provider agencies, and attending community members of their opportunity to call in and participate in the survey. The OA also sent flyers to consortia fiscal agents and contracted provider agencies, who, in turn, distributed the flyers to clients. Those clients, who were also planning body members, were encouraged to participate in both surveys. As an incentive, the first 300 respondents received a 10-minute calling card. A total of 373 respondents representing clients, planning body members, and provider agencies participated in the study and provided valuable information on consortia policies and procedures, underserved populations, access to services, barriers to care, and client satisfaction.

Consortia Efficiency

The consortia's policies, procedures, and organizational structures are important, as they must lead to the desired result -- the development and implementation of community-wide service plans that meet

the needs of PLWHA and their families. Hypotheses developed to answer questions regarding the efficiency of planning bodies include:

1. Planning bodies are more efficient if they have members with more than one year of planning body experience.
2. Urban planning bodies are more efficient than rural.
3. Planning bodies serving large numbers of clients are more efficient than those serving small numbers.
4. Efficient planning bodies have several funding sources.
5. Conducting a resource inventory makes a planning body more efficient.

Planning body members were surveyed on consortia operational procedures, organizational structure, and needs assessments. For example: Does the planning body provide for public comment at its regular meetings? Do people usually show up to participate in public comment? Does the planning body conduct annual self-evaluations? Has the consortium conducted a needs assessment in the last year? Does the planning body conduct a resource inventory? Factor analysis identified 16 variables that loaded onto one efficiency factor. A reliability test confirmed that these items were highly correlated with the factor and they were then used to construct an efficiency scale.

After determining each consortium's efficiency score, statistical tests were computed to examine the relationship between efficiency and our hypothesized variables. We found that conducting a resource inventory before selecting services to fund was significantly associated with efficiency. There was also a significant relationship between efficiency and basing funding decisions on identified service needs.

Consortia Effectiveness

Client satisfaction, operationalized by calculating percent of needs met, was identified as a valid measurement of effectiveness since one of the primary goals of the consortia model is to provide needed services for PLWHA and their families. To evaluate the effectiveness of the consortia model, the OA surveyed clients using a client satisfaction tool. Hypotheses developed to answer questions regarding the effectiveness of planning bodies include:

1. Urban planning bodies are more effective than rural planning bodies.
2. There is a relationship between planning body effectiveness and client's age, gender, and income.
3. Planning bodies serving a larger number of PLWHAs are more effective than planning bodies serving a smaller number of PLWHAs.
4. The longer a client lives in their current county of residence, the higher the percentage of met needs.
5. Clients who participate in annual needs assessments have a higher percentage of met needs than clients who do not participate in annual needs assessments.
6. Clients who attend planning body meetings have a higher percent of met needs than clients who do not attend planning body meetings.

The client satisfaction survey included several questions on the types of services clients were receiving, types of services they needed but were not receiving, and the quality and accessibility of the services. The survey also included questions on client participation in needs assessments and consortium involvement. Based on their responses to questions on 19 different services, the dependent variable 'percent of needs met' was computed and used as the measurement for effectiveness.

Only 44 of the 286 (15%) clients who responded to the survey reported having less than 50% of their needs met with 46% having at least 80% of their needs met. Our analysis found that participation in annual needs assessments proved to be significantly associated with clients' needs being met.

DISCUSSION

We developed an efficiency scale comprised of 16 highly correlated indicators of planning body efficiency. This scale identifies important planning body components and may provide guidance to others evaluating consortia with the goal of improving planning body procedures and direct services. Our findings indicate that an **efficient** planning body is more likely to (a) consist of members who conduct a resource inventory and (b) make funding decisions based on identified needs. We identified one component influencing consortia **effectiveness** – participation in needs assessments.

The importance of conducting an annual needs assessment cannot be overlooked when attempting to identify consortia typologies that are highly efficient. Because the needs assessment process is cumbersome, particularly in a model based on volunteers who often have little or no experience in this field, it may be more beneficial if conducted by an outside agency. A standardized needs assessment tool would be more objective and may lessen a client's apprehension about participating in the needs assessment process. Also time, effort, and expense may be minimized if the needs assessment is conducted by one agency.

These findings may have major implications for California's HIV Care Consortia program as the OA considers consolidating various state and Title II funded programs. Also, the efficient and effective consortia typologies identified here may be useful to other RWCA grantees, and replication of the study and/or its measures may assist in evaluating the validity of the selected factors.

Future studies would benefit from a probability sample of consortia members to insure adequate representation for each consortium. Also, obtaining early buy-in on from the consortia community, (i.e., members, clients, fiscal agents and providers) would help ensure a high response rate when queried for information regarding policies and procedures. The consortia clients who responded were very appreciative of the incentive offered for their participation in the survey. We strongly recommend including an appropriate incentive to increase the number of respondents if a similar survey is conducted.

Our findings contain important policy implications, and they support the need to develop uniform evaluation tools, which can be used consistently among planning bodies. This study developed such a tool which, with some modifications, could be used as the foundation for developing other tools to measure planning body efficiency.

These discussions demonstrate the need for consistent measures of planning body efficiency and the need to identify factors contributing to both efficiency and effectiveness. Additional consortia evaluations are recommended to shed light on the role of the factors we identified as well as identify new factors that may influence efficiency and effectiveness.

An Evaluation of California's Consortia Model
California Department of Health Services, State Office of AIDS

BACKGROUND

Changing Facets of HIV

No longer labeled a gay man's disease, HIV infects an increasing population of heterosexuals and intravenous drug users. California, which currently represents 17% (110,120 as of December 31, 1998) of the cumulative AIDS cases reported in the United States, is currently witnessing this trend of increasing heterosexual transmission. In 1998, 8.1% of the 3,352 newly reported cases were heterosexual as compared to 2.5% of the 9,025 new cases reported in 1990. Also, the percentage grew from 8.1% in 1990 to 14.7% in 1998 for diagnosed heterosexual injection drug users while the MSM/bisexual injection drug users declined from 8.7% in 1990 to 6.1% in 1998. Finally, the fastest growing new group of AIDS patients in the U.S. is women. In California, the percentage of women diagnosed with AIDS increased from 5.1% of the total reported cases in 1990 to 12.3% in 1998. Men comprised 87.7% of the new cases reported in 1998, a drop from 94.9% in 1990.[1]

In 1996, several new drugs were approved and made available to treat persons living with HIV/AIDS (PLWHA). The use of these drugs in conjunction with a strict therapeutic regimen has improved the quality of life for **some** PLWHA; however, many individuals are intolerant of these strict regimens. Some of the new drugs have also prevented and/or treated opportunistic infections among PLWHAs. Hence, the new drug therapies partially account for the decline in AIDS deaths in California, which fell 60% between the first half of 1996 and the first half of 1997.[2] While there has been a decrease in California AIDS deaths, new infections are occurring every year. The introduction of these drug therapies has made it possible for many PLWHAs to live longer. Therefore, a lower mortality rate

coupled with new cases equates to more PLWHAs. The introduction of drug therapies not only changes their life expectancy but also influences the care and treatment needs of PLWHAs.

In light of the changing facets of HIV disease, it is appropriate to evaluate care and treatment models that were developed for a disease that has drastically changed. One such care and treatment model is the HIV Care Consortia Program.

The Ryan White CARE Act

In 1990, Congress passed the Ryan White Comprehensive AIDS Resources Emergency Act (RWCA). The purpose of the RWCA is to provide emergency assistance to localities that are disproportionately affected by HIV disease. To accomplish this goal, the RWCA made financial assistance available to states, eligible metropolitan areas (EMAs), university clinics, and other public or private nonprofit entities. The purpose of this financial assistance was to provide for the development and coordination of efficient and effective systems for the delivery of essential services to individuals and families with HIV disease. The RWCA consists of five Titles and is administered by the HIV/AIDS Bureau, Health Resources and Services Administration (HRSA). Title II of the RWCA provides for establishment of the AIDS Drug Assistance Program, the Home and Community Based Care Program, the Health Insurance Continuation Program, and the HIV Care Consortia Program. This study focuses on the HIV Care Consortia Program, which the RWCA defines as "an association of one or more public and one or more private, nonprofit health organizations in areas most affected by HIV disease."

Reauthorized by Congress in 1996, the RWCA continues to provide for the establishment and support of HIV Care Consortia. In preparation for the year 2000, when the RWCA will again go before Congress for reauthorization, it is vital that we evaluate the consortia model to determine whether it is meeting its objectives.

According to the legislation, the consortium is required to "address the special care and service needs of the populations and subpopulations of individuals and families with HIV disease." The

performance of the consortium must be examined, as it is the consortium's responsibility to develop a service plan that will serve the community and to fund the service providers who implement the service plan. The consortium, then, must be able to accomplish these desired results; hence, the **effectiveness** of the consortium must be evaluated. Furthermore, these desired results must be produced with a minimum of effort, expense, or waste; hence, the **efficiency** of the consortium must be examined.

In July of 1997, the Office of AIDS (OA) responded to a HRSA Request for Quotation which was soliciting proposals for several research projects including an evaluation of the consortia model. The OA was successful in its response, which outlined a method for evaluating the efficiency and the effectiveness of the consortia model. One objective of the study was to describe the factors contributing to the consortium's efficiency and effectiveness. Another objective of the study was to investigate any differences in efficiency and/or effectiveness between consortia typologies. A final outcome of the study was to develop an instrument to be used by other states to evaluate their consortia.

California's Consortia Structure

The Department of Health Services, OA, is the grantee for California RWCA funds. California's planning body structure is rather complex. California currently has 34 consortia, nine of which are Title I EMAs. As of Fiscal Year 1997, an area was required to have more than 2,000 cumulative AIDS cases reported in the most recent five-year period and a population of at least 500,000 to qualify as an EMA. Title I EMAs have planning bodies called Planning Councils. These planning councils operate similar to Title II consortia with some exceptions. For example, 25% of the planning council membership must consist of PLWHAs. This requirement does not exist for Title II consortia. Also, Title I EMAs receive funding directly from HRSA as well as Title II funds from OA. Title II HIV Care Consortia do not receive Title I funds from HRSA.[3]

Consortia's geographic areas consist primarily of counties. While California has 58 counties, OA has encouraged some neighboring counties to form multi-county consortia to more effectively serve PLWHAs. Currently, there are nine multi-county consortia in California.

Until 1996, Title II grantees were required to allocate 50% of their Title II award to the HIV Care Consortia program. This requirement was removed in the reauthorized RWCA.

After receiving its annual award from HRSA, the OA uses a formula allocation process to distribute funds to consortia. Each consortium is responsible for conducting a needs assessment and setting priorities to determine local services. Each consortium has a lead agency referred to as the fiscal agent. The fiscal agent is responsible for administering the consortium's contracts for RWCA funds. Each consortium's fiscal agent contracts with the appropriate service provider agencies depending on local needs. Hence, the number and type of contracted provider agencies may change each fiscal year. California consortia currently contract with over 220 service providers in both Title I and Title II areas.

LITERATURE REVIEW

A review of the literature reveals that other evaluation studies have been conducted to determine the success of the RWCA in meeting the service needs of PLWHAs. In 1994, the San Francisco Department of Public Health, AIDS Office, surveyed 1,056 PLWHAs who received RWCA-funded services at 71 of the 89 RWCA-funded sites.[4] The sample included a large proportion of clients representing women as well as people of color. The purpose of the study was to determine if the process used by the Planning Council was effective in providing appropriate services to specific target populations – poor, primarily uninsured or underinsured, with multiple service needs. This planning council process consists of conducting a needs assessment, setting service priorities, allocating funds to prioritized services, and conducting annual self-evaluations. This study focused on the effect of changing the prioritization of services. Researchers found that RWCA funds were indeed serving the identified target populations once the Planning Council made these services a priority. The use of RWCA funds appeared

to fulfill two of the greatest needs of San Francisco's PLWHA population: medical care services and food. These services were allocated a large percentage of RWCA funds by the Planning Council. By changing funding priorities, the Title I Planning Council was able to fund more services for women and persons of color. Hence, the study found that RWCA funds helped to provide equal access to services for women and ethnic minorities. The study concluded that the Planning Council, which is ethnically diverse and includes many community members and PLWHAs, helped to equalize access for women and ethnic minorities.

In 1997, Montoya et al. conducted an analysis of the RWCA needs assessment in Texas.[5] This study examined the effects of socioeconomic and demographic factors related to unmet needs for current medical, social, and counseling services. The researchers found that most clients with unmet *medical service* needs were low-income Hispanic clients. However, clients with unmet *social service* needs and unmet *counseling* needs were higher income clients, often with private insurance. These unmet needs were attributed to program eligibility requirements since the RWCA is the payer of last resort and has income eligibility requirements. This study produced conflicting results. The Texas needs assessment was successful in identifying higher income clients but was unsuccessful in identifying the most needy clients, (i.e., low income Hispanics in need of medical services).

In 1994, the School of Public Health at the University of California, Berkeley conducted a case study of the Title I Planning Council in Oakland (Oakland Planning Council), California consisting of Alameda and Contra Costa counties.[6] It is important to note that this study was conducted in the first year of the Planning Council's organization. Like many organizations based on consensus and community input, the Oakland Planning Council experienced a great deal of confusion during the first stages of development.

The qualitative analysis found a great inconsistency between the "rational, linear planning model embedded in the RWCA" and the actions of the Oakland Planning Council. The study concluded that

there were many factors contributing to this inconsistency. Some of those factors included confusion among council members regarding the Planning Council's responsibilities and authority, allegations of conflict of interest among members of the Planning Council, concerns about membership representativeness, conflicting demands for services for HIV-infected individuals, and the Planning Council's inability to follow meeting policies and procedures. Furthermore, there were struggles between factions within Alameda County and between Alameda and Contra Costa Counties. While the Planning Council was able to meet its Title I obligations and provided increased medical and social services for PLWHAs, the Planning Council had to be completely reorganized as the confusion among members consumed a considerable amount of time and energy.

These studies did not analyze performance measures or indicators of the efficiency and effectiveness of HIV Care Consortia. Again, the characteristics of the HIV epidemic have drastically changed since the RWCA was first enacted. As both the 1990 RWCA and the reauthorized RWCA (1996) continue to provide for the establishment and support of consortia, it is essential to evaluate the efficiency and effectiveness of the consortia model and to identify any indicators that influence efficiency and effectiveness.

METHODS

Research Design

Research Questions - Efficiency

Several research questions are relevant in determining consortia efficiency. What performance measures or indicators can be used to describe consortium efficiency? Can indicators such as an individual's understanding of the planning body's (consortia/planning council) policies, procedures, mission, definition of conflict of interest, operational structure, and procedures for addressing grievances be used as reliable measures of consortium efficiency? Also, what factors influence consortium efficiency? We developed the following hypotheses to answer these questions:

- Planning bodies whose members have more than one year of planning body experience are more efficient than planning bodies with newer or less experienced members.
- Urban planning bodies are more efficient than rural planning bodies.
- Planning bodies serving large numbers of clients are more efficient than planning bodies serving small numbers of clients.
- Efficient planning bodies have more funding sources than inefficient planning bodies.
- Planning bodies that conduct a resource inventory are more efficient than planning bodies that do not conduct a resource inventory.

These hypotheses led to the testing of several independent variables to determine their relationship on the dependent variable, efficiency.

- Planning Body Experience
- Rurality
- Number of Clients Served
- Number of Funding Sources
- Resource Inventory
- Funding Decisions Based on Identified Needs
- Funding Decision Explanation
- Fiscal Agent Process Fair and Impartial
- Adequate System of Care
- Flexible Service Delivery System

Research Questions - <u>Effectiveness</u>

We operationalized effectiveness by computing the percent of needs met for clients receiving RWCA services. A planning body was considered effective if its clients identified themselves as receiving a high percentage of needed services.

We developed several research questions to address planning body effectiveness. What factors influence a planning body's effectiveness? Does the type of planning body (Title I Planning Council versus Title II HIV Care Consortia) influence effectiveness?

We developed the following hypotheses to answer these and other questions:

- Urban planning bodies are more effective than rural planning bodies.
- There is a relationship between planning body effectiveness and age, gender, and income of PLWHA who receive consortia services.
- Planning bodies serving a larger number of PLWHAs are more effective than planning bodies serving a smaller number of PLWHAs.
- The longer a client lives in their current county of residence, the higher the percentage of met needs.
- Clients who participate in annual needs assessments have a higher percentage of met needs than clients who do not participate in annual needs assessments.
- Clients who attend planning body meetings have a higher percent of met needs than clients who do not attend planning body meetings.
- Clients who are HIV+ have a higher percent of met needs than clients who are HIV-.

These hypotheses led to the testing of several independent variables to determine their influence on the dependent variable, effectiveness.

- Type of Planning Body (Title I/Title II)
- Rurality
- Age
- Gender
- Income
- Status of HIV Disease
- Length of Residence
- Participation in Needs Assessments
- Planning Body Attendance

Description of Survey Tools/Procedures for Gathering Data

We developed two telephone survey instruments to collect information from two groups of people: clients receiving RWCA services (Client Survey – Appendix A) and consortium/planning council members (Consortia Survey – Appendix B). The surveys were designed for planning body members and

clients to phone in and answer questions about their involvement with consortia and consortia providers. They were developed using *HRSA's Consortium Guidance Manual, OA's Title II Consortium Guidance Manual*, and input from staff of the California State University, Sacramento, Institute for Social Research (ISR). We pretested the questionnaires by randomly selecting 20 consortium/planning council members and ten clients, most of who were members of the HIV Comprehensive Care Working Group (an advisory group to the OA). The pretest surveys were administered via telephone by OA staff. After conducting the pretest, the *Consortium/Planning Council Survey* (developed to measure consortium efficiency) consisted of 210 questions. The *Client Survey* (developed to measure consortium effectiveness) consisted of 268 questions. Standard questions on both surveys included age, sex, race, income, and consortium membership.

The sampling design for the study was a non-probability design (convenience sampling); all respondents were self-selected. At the time of the study, there were 180 providers contracting with the OA to provide Title II services. We created a flyer to notify potential respondents of the purpose of the study, phone bank days and hours of operation, and the toll free number (Appendix C). Using client counts from the 1997 Annual Administrative Report (97 AAR) to HRSA, we sent each provider agency enough flyers to distribute to half of the clients on their mailing list. About 3,400 flyers were distributed to planning body members and provider agencies who, in turn, sent the flyers to clients. OA staff also attended several consortium/planning council meetings and distributed flyers to attendees.

The first 300 respondents were entitled to a free telephone calling card. To receive their calling card, callers had an option of either sending a postcard to OA indicating a mailing address (not necessarily their own) or leaving a name and address with the interviewer. Respondents leaving their mailing information with the interviewers were assured that the name given to the interviewer would not be linked to their survey responses.

English and Spanish speaking interviewers from the ISR were trained to answer the phone calls and log the information into a database. Phone records were blocked to ensure respondent confidentiality. At the beginning of each call, interviewers briefly explained the purpose of the survey and obtained the caller's informed consent to participate in the study. While the survey was designed and pretested to last about 25 minutes, the average interview time was 45 minutes. Respondents were willing and often anxious to share their experiences. If a respondent called in when the phone banks were closed, they were prompted to leave a name and a number where an interviewer could return the call. Also, several interviewers returned phone calls during non-posted hours to accommodate respondents.

A protocol was written and submitted to the California Department of Health Services' Committee for the Protection of Human Subjects prior to the start of the survey. The Committee reviewed the protocol and granted its approval.

Generalization to Target Population

As previously mentioned, our study consisted of a nonprobability sampling design. It is important to note that most respondents were self-selected and our sample could differ systematically from our target population. The calculated efficiency and effectiveness scores for some consortia are based on the responses of a very small number of members/clients.

Finally, our sample size of 286 clients and 77 planning body members was relatively small. For example, the 1997 AAR estimated that California served approximately 38,000 duplicated clients. Also, we estimated that approximately 1,211 planning body members were active in California at the time of the study. It is not possible to calculate a response rate as the number of clients and planning body members who were informed of the survey is unknown.

Measurement

Efficiency

Efficiency – Scale Development

Several survey questions were used to define operational procedures, organizational structure, and needs assessments. For example, planning council members, consortium members, fiscal agents, and provider agencies were asked the following questions: Does the planning body provide for public comment at its regular meetings? Do people usually show up to participate in public comment? Does the planning body conduct annual self-evaluations? Has the consortium conducted a needs assessment in the last year? Does the planning body conduct a resource inventory? Factor analysis identified 16 variables that were highly inter-correlated and loaded onto one factor (Table 1). A reliability test confirmed that these items were highly correlated with the factor ($\alpha = .9448$) and they were then used to construct an efficiency scale.

TABLE 1
Variables Included in the Efficiency Scale

	VARIABLES
1	Understanding of planning body's policies.
2	Understanding of planning body's procedures.
3	Understanding of planning body's mission
4	Understanding of how the planning body's mission is to be accomplished.
5	Understanding of planning body's formal definition of conflict of interest.
6	Understanding of the plan developed to manage conflict of interest.
7	Understanding of the procedures for addressing grievances.
8	Understanding of the basic operational structure, such as by-laws and decision-making processes.
9	Establishment of a sufficient number of committees.
10	Planning body's actions are driven by committee recommendations.
11	Planning body provides for public comment at its regular meetings.
12	Planning body carefully reviews epidemiological data.
13	Planning body conducts annual self-evaluations.
14	Planning body is able to work through various opinions brought to the table.
15	Familiarity with procedures used for setting service priorities.
16	Satisfaction with procedures for setting service priorities.

Possible responses to each of the 16 items were on a four-point scale ranging from strongly agree to strongly disagree. A score of 1 or 2 indicated agreement with the item while a score of 3 or 4 indicated disagreement. The scale score was calculated by summing up the responses on the 16 items then dividing by the number of valid responses for each respondent.

Analysis - Description of Statistical Techniques

Analyses were conducted using the efficiency scale as the dependent variable. Several independent variables were first tested to determine their relationship with efficiency. The chi-square statistic was computed to test the relationship between efficiency and two independent variables: type of consortium (urban/rural) and length of planning body experience. Separate *t*-tests were computed to examine the relationship between number of clients served and number of funding sources with efficiency.

Next, multiple regression was used to explain the relationship between consortium efficiency and two independent variables: planning body experience and conducting a resource inventory (documenting other available resources in the community before choosing specific services to fund).

Finally, funding decisions (basing funding decisions on identified service needs) were explored to determine what relationship they had on efficiency. Only those relationships with $p \leq .05$ were considered statistically significant. All analyses were conducted using either SAS or SPSS.

Effectiveness

Effectiveness – Percent of Needs Met

The dependent variable 'percent of needs met' was computed and used as the measurement for effectiveness. We examined the following research questions to determine consortia effectiveness: Are clients receiving needed services? How many services are needed but are not received by clients? Respondents were asked several questions regarding each of the 19 services listed in Table 2.

TABLE 2
Services Included in the Effectiveness Score

	SERVICES
1	Case Management
2	AIDS Drug Assistance Program (ADAP)
3	Mental Health
4	Substance Use Treatment or Counseling
5	Rehabilitation
6	Client Advocacy (including Benefits Counseling)
7	Service Outreach or Secondary Prevention Counseling
8	Other Counseling (not Mental Health)
9	Home Health Care
10	In-Home Hospice
11	Residential Hospice
12	Day or Respite Care
13	Buddy Companion
14	Food Bank/Home Delivered Meals/Nutritional Counseling
15	Transportation
16	Emergency Financial Assistance
17	Dental
18	Housing
19	Medical (Personal Physician)

The development of the effectiveness measurement focused on two questions: "Did you receive the service? If not, why?" Respondents were given a list of responses to this question, including "I don't need the service." All other choices were indications of need i.e., "Not available in the consortia service area," "Too far," "Denied service" etc. The responses to each of the service questions were used to develop the effectiveness measure – percent of needs met. This variable was calculated by dividing the total number of services received by the number of needed services.

Analysis - Description of Statistical Techniques

The chi-square statistic was computed to test the relationship between effectiveness (percent of needs met) and the following independent variables: type of consortium (Title I/Title II), rurality (urban/rural), length of current county of residence, participation in needs assessment, and number of planning body meetings attended. Several demographic variables were also tested including age, gender, income, and status of HIV disease.

FINDINGS

Respondent Characteristics

We distributed over 3,400 flyers to planning body members and provider agencies who, in turn, sent the flyers to clients. The distribution of flyers resulted in 373 respondents who called in and completed the survey (Table 3). There were 278 (75%) callers who identified themselves as clients receiving RWCA services while eight respondents identified themselves as family members calling in to participate on behalf of a client. Three respondents identified themselves as care givers (a person caring for a client who needed assistance in responding to the survey). Of the remaining sample, 20% identified themselves as planning body members, fiscal agents, or employees of a provider agency and three percent identified themselves as "other," i.e., persons who attended planning body meetings but did not identify themselves as official members. Some consortia members were also clients for a total of 286 clients.

TABLE 3
Respondent Classification

	N	*%*
Client	278	75
Family Member/ Care Giver	8	2
Planning Body Member/ Fiscal Agent/Provider	77	20
Other	10	3
Total	373	100

Nearly all the client respondents (99%) identified themselves as HIV+ (Table 4). Almost half of these respondents also identified themselves as having AIDS (44%). Finally, more than half of the clients (66%) were receiving services in the county where they were diagnosed with AIDS.

TABLE 4
Specific Client Characteristics

	N	*%*
***Question /* Response**		
Respondent has HIV:		
HIV+	282	99
HIV-	2	1
Don't Know	1	0
Decline to Answer	1	0
Total	286	100
Status of HIV:		
HIV+ Minor/No Symptom.	85	30
HIV+ Sympt./Not AIDS	65	23
AIDS	125	44
Other	4	2
Don't Know	3	1
Decline to Answer	0	0
Total	282	100
Receive Services in County where Diagnosed:		
Yes	83	66
No	42	34
Total	125	100

Over half of the respondents were between the ages of 35 and 54. As Table 5 illustrates, the majority of the client respondents (80%) were male while the majority of the planning body respondents were female (65%). In both populations, the majority of the respondents were white (65% and 71%, respectively). Also, the majority of both client respondents and planning body respondents were not of Hispanic origin (77% and 82% respectively). Finally, as expected, most of the clients (84%) had a 1997 household income of $20,000 or less while over half of the planning body respondents had a 1997 household income of more than $40,000.

TABLE 5
RESPONDENT CHARACTERISTICS

	Client		*Planning Body Member*	
Gender	N	%	N	%
Male	230	80	27	35
Female	5	2	50	65
Other	1	1	0	0
Missing	50	17	0	0
Total	286	100	77	100
Race				
White	185	65	55	71
Black	51	18	5	6
Asian/Pacific Islander	1	0	3	4
Native American	8	3	5	7
Other	36	13	7	9
Declined to Answer	5	1	2	3
Total	286	100	77	100
Hispanic Origin				
Yes	63	22	13	17
No	220	77	63	82
Don't Know	3	1	1	1
Total	286	100	77	100
Age				
13-19	1	3	1	1
20-34	58	20	11	14
35-44	134	46	26	34
45-54	67	23	27	35
55-64	24	8	9	12
65+	1	0	2	3
Declined to Answer	1	0	1	1
Total	286	100	77	100
Income				
<$5,000	60	22	0	0
$5,001-$10,000	116	41	2	3
$10,001-$20,000	61	21	4	5
$20,001-$30,000	18	6	6	8
$30,001-$40,000	8	3	11	14
$40,001-$50,000	7	2	16	21
$50,001+	9	3	32	41
Declined to Answer	7	2	6	8
Total	286	100	77	100

Client respondents were asked to rate the quality of care for services received (see Appendix D) on a scale of one to five with one being very good and five being very bad. Of the 286 HIV+ respondents, nearly all reported using primary medical care services (266) and case management services (238). On average, clients utilized primary medical care services 11 times within the last 12 months. Most clients rated the quality of primary care services as very good to good (mean score 1.5). The clients who reported utilizing case management services saw their case manager an average of 12.5 times within the last 12 months. These clients were satisfied with the quality of case management care, with a mean score of 2.0. Home health was the least utilized service of this client population. Although less than seven clients utilized this service, clients reported being satisfied with mean scores of 1.7.

Results of Efficiency Analysis

Consortia/planning councils were divided into three ranks based on their overall efficiency score obtained from averaging scores from members of their consortium. Planning bodies in Rank 1 had higher scores for efficiency while Rank 3 planning bodies had the lowest scores. There were twelve planning bodies in Rank 1 and nine planning bodies in Rank 3. Separate *t*-tests were computed to examine the relationship between efficiency and the number of clients served and the number of funding sources. Table 6 illustrates the lack of a significant relationship between these independent variables and efficiency.

TABLE 6
Significance of Selected Characteristics on Top and Bottom Third Consortia

	Rank 1		***Rank 3***			
	N	Mean	N	Mean	*t*-Test	P
# of Clients Served	12	404	9	3324.78	-1.5081	.16
# of Funding Sources	12	2.57	9	2.087	.4245	.67

The chi-square statistic was computed to test the relationships between efficiency and type of consortium (rural/urban) and years of planning body experience. As indicated in Table 7, there was no significance in the relationship between type of consortium (rurality) or years of planning body experience and efficiency score.

TABLE 7
Significance of Selected Characteristics on Top and Bottom Third Consortia

	Rank 1		*Rank 3*			
	N	%	N	%	X^2	P
Rurality						
Urban	8	67	6	67		
Rural	4	33	3	33		
Total	12	100	9	100	.0 NS	1.00
Planning Body Experience						
<1 Year	1	4	2	8		
1-2 Years	3	12	7	29		
3-4 Years	6	24	4	17		
5+ Years	14	56	10	42		
Unknown	1	4	1	4		
Total	25	100	24	100	2.981 NS	.56

The first set of analyses, then, indicated that there were no significant relationships between the independent variables and efficiency. A second analysis was conducted using multiple regression (Table 8). This analysis confirmed the findings from the first analysis: rurality, planning body experience, number of clients served, and number of funding sources were not associated with efficiency. The R^2 value was small (.036) indicating that the independent variables taken together explained very little of the variance in efficiency.

TABLE 8
Regression Analysis on Efficiency (N=74)

Variable	*Efficiency Scale*
Rurality	
Rural	0.164
Urban	0.048
Planning Body Experience	
0 - up to 1 year	-0.038
1 - up to 3 years	0.233
3+ years	-0.192
Number of Clients Served	0.019
Number of funding Sources	0.015
Adjusted R^2	0.036

***Standardized regression coefficients are shown.**

The final regression analysis explored funding issues and efficiency. As the results in Table 9 show, conducting a resource inventory before choosing services to fund was significantly associated with efficiency as consortia that conducted a resource inventory had higher efficiency scores. There was also a significant relationship between basing funding decisions on identified service needs and efficiency. The remaining independent variables that were tested did not prove to be significantly associated with efficiency. However, the R^2 value was relatively high (.646) indicating that all of these independent variables measuring funding decisions, taken together, explains almost two-thirds of the variance in efficiency.

TABLE 9
Regression Analysis of Efficiency Scale (N=74)

Variable	*Efficiency Scale*
Resource Inventory	0.243[a]
Funding Decisions Based on Needs	0.501[a]
Funding Decision Explanation	-0.054
Fiscal Agent Process	0.153
Adequate System of Care	0.104
Flexible Service Delivery System	-0.014
Adjusted R^2	0.646

***Standardized regression coefficients are shown.**
[a] p <= .01

Results of Effectiveness Analysis

The next set of analyses examined the measure of effectiveness – percent of client needs met. Most of the respondents reported a high percentage of needs met (Table 10). Only 15.4% reported having less than 50% of their needs met, while 46% of the respondents reported having at least 80% of their needs met.

TABLE 10
Clients Percent of Needs Met

% of Needs Met	N	%
< 50%	44	15.4%
50-59%	26	9.1%
60-69%	48	16.8%
70-79%	35	12.2%
80-89%	61	21.3%
90-99%	11	3.8%
100%	61	21.3%
Total	286	100%

Separate chi-square tests were computed to examine the relationship between effectiveness and the independent variables. Table 11 illustrates that there was no significant relationship between effectiveness and the following independent variables: type of planning body (Title I/Title II), rurality (urban/rural), gender, age, and income. While not included in the table, there was a significant relationship between HIV status and percent of needs met. Persons who were HIV+ were more likely to have their needs met than persons who were not HIV+. This finding should be noted with caution, however, because there was a small number of respondents (n=2) representing the HIV- or family member client population.

TABLE 11
Significance of Selected Characteristics on Percent of Needs Met

	N	%	X^2	P
Type of Planning Body				
Title I	79	28		
Title II	199	72		
Total	278	100	3.174 NS	0.366
Rurality				
Urban	241	87		
Rural	35	13		
Total	276	100	2.262 NS	0.520
Gender				
Male	226	81		
Female	52	19		
Total	278	100	2.868 NS	0.412
Age				
20-34	56	20		
35-44	130	47		
45-54	67	24		
55+	25	9		
Total	278	100	12.251 NS	0.200
Income				
<=$5,000	60	22		
$5,001-$10,000	114	42		
$10,001-$20,000	58	21		
$20,001-$30,000	17	6		
$30,001+	23	9		
Total	272	100	13.845 NS	0.311

Chi-square tests were also employed to test the relationship between number of planning body meetings attended, length of county residence, and participation in needs assessments. As Table 12 indicates, there were no significant relationships between meeting attendance and length of county residence with effectiveness. Participation in annual needs assessment, however, was associated with

effectiveness. Respondents who participated in a needs assessment had a higher percent of met needs than respondents who did not participate in a needs assessment.

TABLE 12
Significance of Selected Characteristics on Percent of Needs Met

	N	%	X^2	P
Number of Planning Body Meetings Attended in Last Year				
0	168	60		
1-3	51	18		
4-6	25	9		
7+	35	13		
Total	279	100	8.062 NS	0.528
Length in County of Residence				
< 1 Year	28	10		
1 up to 2 Years	35	13		
2 up to 4 Years	39	14		
4 up to 7 Years	23	8		
7 + Years	152	55		
Total	277	100	18.010 NS	0.115
Participate in Annual Needs Assessment				
Yes	129	81		
No	146	19		
Total	275	100	10.378	0.016

DISCUSSION

General Discussion

We developed an efficiency scale comprised of 16 highly correlated indicators of planning body efficiency (see Table 1). This scale identifies important planning body characteristics and may provide guidance to others evaluating consortia with the goal of improving planning body procedures and direct services. Our analysis indicates that an efficient planning body is more likely to consist of members who conduct a resource inventory and make funding decisions based on identified needs. These indicators can

be used to improve efficiency if planning bodies adopt or meet the policies/procedures listed, such as establishing a clear method for addressing grievances.

The characteristics described above could be used to formulate consortia "typologies." These consortia typologies may be useful to other RWCA grantees and replication of the study and/or its measures may assist in evaluating the validity of the selected efficiency characteristics.

While we have only identified one significant independent variable, participation in needs assesments, many respondents reported a high percentage of met needs. More specifically, 46% of the respondents reported receiving at least 80% of needed services. This finding is pertinent to the RWCA as one of its primary goals is to provide needed services to PLWHAs. This measure of consortium effectiveness, however, simply reflects the number of needed and received services; it is not an indication of quality and accessibility of received services.

Respondents were given the opportunity to provide comments or suggestions on improving the current system of care. A complete list of comments can be found in Appendix E. Perhaps the most frequent comment or suggestion pointed out the need for additional funding. Respondents felt more money was needed not only to provide more direct services but to assist and satisfy the staffing needs of contracted provider agencies. Respondents specifically asked for more funding to support specific ancillary services such as transportation, case management, outreach, and translation services. Many respondents also wanted training and counseling which specifically addressed return-to-work issues. Some respondents reported the need for more services for women, children, Latinos and IV drug users. Housing, food bank or food vouchers, and buddy/companion services were also identified as important needs that deserve more funding. Education, increased awareness, knowledge and compassion among community members were echoed throughout the responses. In addition, most respondents reported a heavy reliance on their case managers, with most respondents indicating they were very satisfied with them. Some respondents recommended that it would be helpful to have both HIV case management and

nurse case management since each provides its own area of expertise. In this way, clients would benefit from having both a social case manager and a nurse case manager with HIV expertise. Respondents requested more HIV education for physicians and/or better access to HIV specialists. Several respondents expressed the desire to access services at one location. One respondent referred to this as the "under one roof concept." They felt that receiving services at one location would provide confidentiality as well as the receipt of prompt care. This would also reduce the amount of transportation needed, as clients would only have to go to one location.

Respondents also provided comments about their local planning bodies. Many felt that there were too many "turf battles" or "political issues" between providers. Some felt that the distribution of funds among several different agencies was wasteful and duplicative. Perhaps one of the most common responses involved the need for increased HIV representation on consortia/planning councils. Respondents often did not attend meetings because a selected group controlled them, and they did not feel comfortable or understand the planning bodies' procedures or structure. Many were not comfortable in relaying their needs to the planning body and were afraid to bring any grievances to the table. Furthermore, respondents felt that the needs assessments in some areas were manipulated to yield specific results. Some suggested that needs assessments be conducted more than once a year and should be conducted by an outside agency such as the OA. They would also like to have the planning bodies evaluated at least once a year by an outside agency. Finally, respondents expressed the need to have planning bodies more heavily monitored to ensure compliance.

These responses support the need to develop uniform evaluation tools which can be used consistently among planning bodies. This study developed such a tool which, with some modifications, could be used as the foundation for developing other tools to measure planning body efficiency.

Lessons Learned

Future studies would benefit from a probability sample of consortia members to insure adequate representation for each consortium. In addition, a probability sampling design would allow for the computation of response rates. Obtaining buy-in early on from the consortia community, i.e., members, clients, fiscal agents and providers, will help ensure a high response rate when queried for information regarding policies and procedures. The consortia clients who responded were very appreciative of the incentive offered for their participation in the survey. We strongly recommend including a relevant incentive to increase the number of client responses if a similar survey is conducted.

Policy Implications

The current consortia model relies on community-wide involvement. Unfortunately, the "voice of the community" is not always heard. As pointed out by some of the callers, clients are often afraid, uncomfortable, confused, burned out, or do not have the time or energy to participate in planning body meetings. Also, many of the important duties of the planning bodies are performed by volunteers or persons with little experience in needs assessments, prioritizing services, and allocating funds.

The results of this study revealed two factors contributing to efficiency and one factor contributing to effectiveness. Each of these factors rely on the development, administration, and interpretation of the planning body's needs assessment, a task which is often taken on by members with little or no experience in this area.

Currently, the OA gives smaller consortia the option of spending an additional 5% of its annual allocation to conduct needs assessments; all other consortia must pay for this activity from a 10% cap for administration and needs assessments. Few planning bodies, however, use the money for these purposes and are, therefore, still challenged with the task of performing a useful needs assessment. Conducting a needs assessment requires several steps. First, the planning body must inform clients, both continuing and potential, of the needs assessment. This is important as client participation in the needs assessment

increases planning body effectiveness by assuring that client needs are clearly identified to the planning body. Second, a planning body must develop a tool that measures clients' needs, not simply clients' satisfaction. Not only is this survey tool important, but the analysis of the data is important as well. Proper analysis allows the planning body to base its funding decisions on identified needs, a component identified in our study as important in improving planning body efficiency. Once clients' needs are identified, the planning body must prioritize services. Before funding the identified services, the planning body must conduct a resource inventory before deciding which service categories will be funded. For example, a planning body might not fund food bank services if there is a local food bank providing these services to clients. Our findings indicate that conducting resource inventories will also increase the planning body's efficiency.

Because the needs assessment process is cumbersome, particularly in a model based on volunteers who often have little or no experience in this field, it may be more beneficial if conducted by an outside agency. The planning body would review the results and the outside agency could use the same needs assessment tool for all planning bodies. In this way, a client may feel less intimidated as the process would become more objective and planning bodies would not be burdened with such a large task. Clients may feel more comfortable participating in needs assessments when moving to a new area, as they would know what to expect from the needs assessment. A uniform needs assessment tool could minimize time, effort and possibly expense if conducted by one agency. Perhaps a community leader who participated in the development of the RWCA best stated it:

"We wrote the RWCA to insure the participation of people infected and affected by HIV/AIDS in the planning, development, and implementation of HIV/AIDS public policy and programs. We did not

write the RWCA for the community and people with HIV/AIDS to actually DO all the professional level work."[7]

These discussions demonstrate the need for consistent measures of planning body efficiency and the need to identify factors contributing to both efficiency and effectiveness. Additional consortia evaluations are recommended to shed light on the role of the factors we identified and also to identify new factors that may influence efficiency and effectiveness.

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CLIENT SURVEY

AN EVALUATION OF CALIFORNIA'S CONSORTIA MODEL

SURVEY SCREENING

What is your relationship to Ryan White services or the clients receiving them? Are you:

→ a Ryan White client receiving direct services? (If yes, client survey administered).

→a **family member**[1] of a Ryan White client?

If yes, is your family member or client able to call?

If yes, would you encourage them to call? (If yes, thank the caller for encouraging the client/family member to call, and ask the caller if they are receiving services (if yes, give client survey). If not receiving services, ask caller if they are familiar with their local consortium/planning council (if yes, give the consortium/planning council survey).

If no, are you calling to respond on behalf of a client who is receiving Ryan White services? If yes, Would you respond to the interview based on your experiences as a family member? (If yes, shortened version of the client survey administered).
If caller is responding on behalf of client, client survey administered.
We would like you to respond on behalf of your family member. However, if you are receiving Ryan White services as well, you are welcome to work through the survey a second time based on your experiences as a Ryan White client.

→a **care giver**[2] of a Ryan White client?

If yes, is the client able to call?

If yes, would you encourage them to call? (If yes, thank the caller for encouraging the client to call, and ask the caller if they are familiar with their local consortium/planning council and if so the consortium/planning council survey will be administered).

If no, are you calling to respond on behalf of a client who is receiving Ryan White services? If yes, Would you respond to the interview based on your experiences as a care giver? (If yes, shortened version of the client survey administered).
If caller is responding on behalf of client, client survey administered.

→ a consortium/planning council member, a provider, or a fiscal agent? If yes to any, ask: Are you also a client? If yes, client survey administered. If no, give consortium/planning council survey administered.

→If none of the above categories apply: what motivated you to call? (What is the purpose of your call?). Are you familiar with your local area consortium/planning council? Perhaps you would like to participate in the consortium/planning council survey.

Please be assured that no identifying information will connect you to your answers; your responses will be completely confidential. Have you seen the flyer advertising this study? Would you like to hear a little bit about the study (if yes, give background) or would you prefer to begin the survey now?

The **client survey** consists of three parts:

I. Health Care Services
   A. Specific Services
   B. General Services
II. Needs Assessment/Consortium or Planning Council Involvement
III. Demographics

OR

The **consortium/planning council** survey consists of five parts:

I. Membership
II. Policies and Procedures
III. Needs Assessment
IV. Service Delivery
V. Demographics

I will take down all of your additional comments at the end of the survey. You might want to jot down notes to yourself as we go through the survey so that you don't forget to relay them to me. We anticipate the results of this study will be available by May 1999. **THANK YOU FOR YOUR PARTICIPATION!!!**

I. HEALTH CARE SERVICES

(A.) Specific Services

1.) Where do you (family member/care person) obtain most of your (their) routine medical care?
   A. Emergency Room
   B. Hospital based clinic
   C. Community health center or community mental health center
   D. HMO
   E. Solo/group private physician
   F. Other (please specify):_____

2.) Do you (family member/care person) have a personal physician?
   A. Yes (Please go to question 5.)
   B. No
   C. Unknown

3.) Why don't you have a personal physician?
   A. I don't need one.
   B. I don't know if one is available. (Go to question 10.)
   C. There is not one available in my consortia service area. (Go to question 10.)
   D. There is not a physician providing quality care in my consortia service area.
   E. Too much red tape.
   F. The physician is too far.
   G. I do not have transportation.
   H. I am too ill to travel.
   I. I was denied a personal physician.
   J. Other (please specify:_____)

4.) Is there a personal physician available in your consortia service area (CSA)?

A. Yes (Please go to question 10.)
B. No (Please go to question 10.)
C. Unknown (Please go to question 10.)

5.) How do you pay for your personal physician?
A. Medi-Cal
B. Medicare
C. Ryan White
D. Private health insurance
E. Individual funds
F. Other (please specify:_____)
G. Unknown

6.) Is this physician providing the majority of your specialized care for HIV/AIDS treatment?
A. Yes→ Are you comfortable with this physician's ability to treat HIV/AIDS patients?
B. No
C. Unknown

A. Yes
B. No
C. Somewhat

7.) How often have you seen this physician in the last year?_____

8.) Is he/she located in the area served by your consortium?
A. Yes
B. No→ →Are these services available in your consortium service area CSA?
C. Unknown

A. Yes→ →Why do you receive this service in another CSA?
B. No (Please circle all that apply.)
C. Unknown

A. Positive relationship with previous physician
B. Poor quality in CSA
C. Too far
D. Too much red tape
E. No transportation
F. Too ill to travel
G. Denied service in CSA
H. Other (please specify:_____)

9.)

Please rate the following items on a scale from 1 to 5: 1 being very good and 5 being very bad.					
	Very Good				Very Bad
The availability of your physician when you need an appointment?	1	2	3	4	5
The quality of care you receive from your physician?	1	2	3	4	5
The service setting, i.e., comfort level of your physician's office?	1	2	3	4	5
The ease to which you can reach your doctor in an emergency?	1	2	3	4	5

10.) Do you have a case manager?
- A. Yes (Go to question 13.)
- B. No

11.) Why don't you have a case manager?
- A. I don't need one.
- B. I don't know if one is available. (Please go to question 17.)
- C. There is no case manager available in my consortia service area. (Please go to question 17.)
- D. The case manager does not offer quality service.
- E. Too much red tape.
- F. The case manager is too far.
- G. I do not have transportation.
- H. I am too ill to travel.
- I. I was denied a case manager
- J. Other (please specify:_____)

12.) Is there a case manager available in your consortia service area (CSA)?
- A. Yes (Please go to question 17.)
- B. No (Please go to question 17.)
- C. Unknown (Please go to question 17.)

13.) How often have you seen your case manager in the last year?_____

14.) Is he/she located in the area served by your consortium?

A. Yes

B. No→ →Are these services available in your consortium service area CSA?

C. Unknown

A. Yes →→ Why do you receive this service in another CSA? Circle all that apply.

B. No

C. Unknown

A. Positive relationship with previous physician
B. Poor quality in CSA
C. Too far
D. Too much red tape
E. No transportation
F. Too ill to travel
G. Denied service in CSA
H. Other (please specify:_____)

15.)

Please rate the following items on a scale from 1 to 5: 1 being very good and 5 being very bad.					
	Very Good				Very Bad
The availability of your case manager?	1	2	3	4	5
The quality of care you receive from your case manager?	1	2	3	4	5
The service setting, i.e., comfort level of your case manager's office?	1	2	3	4	5
The ease to which you can reach your case manager in an emergency?	1	2	3	4	5
Helpfulness in connecting you with benefits and services?	1	2	3	4	5
The case managerσ knowledge of benefits and services?	1	2	3	4	5

16.) How is the service paid for?

A. Medi-Cal
B. Medicare
C. Ryan White
D. Private health insurance
E. Individual funds
F. Other (please specify:_____)
G. Unknown

17.) Do you receive medications through the AIDS Drug Assistance Program (ADAP)?

A. Yes (Please go to question 20.)
B. No
C. Unknown

18.) Why don't you receive ADAP?

A. I don't need it.
B. I don't know if it is available. (Please go to question 23.)
C. It is not available in my consortia service area. (Please go to question 23.)
D. The service quality is poor.
E. Too much red tape.
F. The pharmacy is too far.
G. There is no enrollment site in my county. (Please go to question 23.)
H. I do not have transportation.
I. I am too ill to travel.
J. I was denied ADAP
K. Other (please specify:_____)

19.) Is there an eligibility screening site in your county?

A. Yes (Please go to question 23.)
B. No→ → →Did you know you can get prescriptions through the mail order program?
C. Unknown (Please go to question 23.)
   A. Yes (Please go to question 23.)
   B. No (Please go to question 23.)

20.)How often have you used ADAP in the last year?_____

21.) Is there an eligibility screening site in your county?

A. Yes
B. No→ → →Did you know you can get prescriptions through the mail order program?
C. Unknown
   A. Yes
   B. No

22.)

Please rate the following items on a scale from 1 to 5: 1 being very good and 5 being very bad.						
	Very Good				Very Bad	Not Applicable
The availability of ADAP covered medications?	1	2	3	4	5	
The quality of care you receive from the pharmacy?	1	2	3	4	5	8
The service setting, i.e., comfort level of pharmacy?	1	2	3	4	5	8
The ease to which you can get emergency refills?	1	2	3	4	5	8

23.) Do you receive dental services?

A. Yes (Go to question 26.)
B. No

24.) Why don't you receive dental services?

A. I don't need it.

B. I don't know if it is available. (Please go to question 30.)
C. There is no dentist available in my consortia service area. (Please go to question 30.)
D. The dentist does not offer quality service.
E. Too much red tape.
F. The dentist is too far.
G. I do not have transportation.
H. I am too ill to travel.
I. I was denied dental care.
J. Other (please specify:_____)

25.) Is there a dentist in your consortia service area (CSA)?
A. Yes (Please go to question 30.)
B. No (Please go to question 30.)
C. Unknown (Please go to question 30.)

26.) How often have you seen the dentist in the last year?_____

27.) Is he/she located in the area served by your consortium?
A. Yes
B. No→ →Are these services available in your consortium service area CSA?
C. Unknown
A. Yes→→ Why do you receive this service in another CSA? Circle all that apply.
B. No
C. Unknown
A. Positive relationship with previous dentist.
B. Poor quality in CSA
C. Too far
D. Too much red tape
E. No transportation
F. Too ill to travel
G. Denied service in CSA
H. Other (please specify:_____)

28.)

Please rate the following items on a scale from 1 to 5: 1 being very good and 5 being very bad.					
	Very Good				Very Bad
The availability of the dentist?	1	2	3	4	5
The quality of care you receive from the dentist?	1	2	3	4	5
The service setting, i.e., comfort level of the dentist's office?	1	2	3	4	5

29.) How do you pay for your dental care?
A. Medi-Cal
B. Medicare

C. Ryan White
D. Private health insurance
E. Individual funds
F. Other (please specify:_____)
G. Unknown

30.) Do you receive mental health/therapy/counseling services?
A. Yes (Go to question 33.)
B. No

31.) Why don't you receive mental health/therapy/counseling?
A. I don't need it.
B. I don't know if it is available. (Please go to question 37.)
C. The service is not available in my consortia service area. (Please go to question 37.)
D. The provider does not offer quality service.
E. Too much red tape.
F. The provider is too far.
G. I do not have transportation.
H. I am too ill to travel.
I. I was denied the service.
J. Other (please specify:_____)

32.) Is there a mental health therapist/counselor in your consortia service area (CSA)?
A. Yes (Please go to question 37.)
B. No (Please go to question 37.)
C. Unknown (Please go to question 37.)

33.) How often have you seen the mental health therapist/counselor in the last year?_____

34.) Is he/she located in the area served by your consortium?
A. Yes
B. No→ →Are these services available in your consortium service area CSA?
C. Unknown
A. Yes→→ Why do you receive this service in another CSA? Circle all that apply.
B. No
A. Positive relationship with previous provider.
C. Unknown
B. Poor quality in CSA
C. Too far
D. Too much red tape
E. No transportation
F. Too ill to travel
G. Denied service in CSA
H. Other (please specify:_____)

35.)

Please rate the following items on a scale from 1 to 5: 1 being very good and 5 being very bad.		
	Very	Very

	Good				Bad
The availability of the mental health therapist/counselor?	1	2	3	4	5
The quality of care you receive from the therapist/counselor?	1	2	3	4	5
The service setting, i.e., comfort level of the therapist/counselor's office?	1	2	3	4	5
The ease to which the therapist/counselor can be reached in an emergency?	1	2	3	4	5

36.) How do you pay for this service?
- A. Medi-Cal
- B. Medicare
- C. Ryan White
- D. Private health insurance
- E. Individual funds
- F. Other (please specify:_____)
- G. Unknown

37.) Do you receive substance use treatment/counseling?
- A. Yes (Go to question 40.)
- B. No

38.) Why don't you receive substance use treatment/counseling?
- A. I don't need it.
- B. I don't know if it is available. (Please go to question 44.)
- C. The service is not available in my consortia service area. (Please go to question 44.)
- D. The provider does not offer quality service.
- E. Too much red tape.
- F. The provider is too far.
- G. I do not have transportation.
- H. I am too ill to travel.
- I. I was denied the service.
- J. Other (please specify:_____)

39.) Is there substance use treatment/counseling available in your consortia service area (CSA)?
- A. Yes (Please go to question 44.)
- B. No (Please go to question 44.)
- C. Unknown (Please go to question 44.)

40.) How often have you used substance use treatment/counseling in the last year?_____

41.) Is the provider located in the area served by your consortium?
- A. Yes
- B. No→ →Are these services available in your consortium service area CSA?
- C. Unknown
  - A. Yes→→ Why do you receive this service in another CSA? Circle all that apply.
  - B. No
    - A. Positive relationship with previous provider.

C. Unknown

B. Poor quality in CSA
C. Too far
D. Too much red tape
E. No transportation
F. Too ill to travel
G. Denied service in CSA
H. Other (please specify:_____)

42.)

Please rate the following items on a scale from 1 to 5: 1 being very good and 5 being very bad.					
	Very Good				Very Bad
The availability of the substance use treatment/counselor?	1	2	3	4	5
The quality of care you receive from the provider?	1	2	3	4	5
The service setting, i.e., comfort level of the provider's office?	1	2	3	4	5
The ease to which this counselor can be reached in an emergency?	1	2	3	4	5

43.) How do you pay for this service?

A. Medi-Cal
B. Medicare
C. Ryan White
D. Private health insurance
E. Individual funds
F. Other (please specify:_____)
G. Unknown

44.) Do you receive rehabilitation services?

A. Yes (Go to question 47.)
B. No

45.) Why don't you receive rehabilitation services?

A. I don't need it.
B. I don't know if it is available. (Please go to question 51.)
C. The service is not available in my consortia service area. (Please go to question 51.)
D. The provider does not offer quality service.
E. Too much red tape.
F. The provider is too far.
G. I do not have transportation.
H. I am too ill to travel.
I. I was denied the service.
J. Other (please specify:_____)

46.) Is there rehabilitation services available in your consortia service area (CSA)?

A. Yes (Please go to question 51.)
B. No (Please go to question 51.)
C. Unknown (Please go to question 51.)

47.) How often have you used rehabilitation services in the last year?_____

48.) Is the provider located in the area served by your consortium?

A. Yes
B. No→ →Are these services available in your consortium service area CSA?
C. Unknown
   A. Yes→→ Why do you receive this service in another CSA? Circle all that apply.
   B. No
      A. Positive relationship with previous provider.
   C. Unknown
      B. Poor quality in CSA
      C. Too far
      D. Too much red tape
      E. No transportation
      F. Too ill to travel
      G. Denied service in CSA
      H. Other (please specify:_____)

49.)

Please rate the following items on a scale from 1 to 5: 1 being very good and 5 being very bad.					
	Very Good				Very Bad
The availability of the rehabilitation services?	1	2	3	4	5
The quality of care you receive from the provider?	1	2	3	4	5
The service setting, i.e., comfort level of the provider's office?	1	2	3	4	5

50.) How do you pay for this service?

A. Medi-Cal
B. Medicare
C. Ryan White
D. Private health insurance
E. Individual funds
F. Other (please specify:_____)
G. Unknown

51.) Do you receive home health care services?

A. Yes (Go to question 54.)
B. No

52.) Why don't you receive home health care services?

A. I don't need it.
B. I don't know if it is available. (Please go to question 58.)
C. The service is not available in my consortia service area. (Please go to question 58.)
D. The provider does not offer quality service.
E. Too much red tape.
F. I was denied the service.

G. Other (please specify:_____)

53.) Are there home health care services in your consortia service area (CSA)?
A. Yes (Please go to question 58.)
B. No (Please go to question 58.)
C. Unknown (Please go to question 58.)

54.) How often have you used home health care services in the last year?_____

55.) Is the provider located in the area served by your consortium?
A. Yes
B. No→ →Are these services available in your consortium service area CSA?
C. Unknown
A. Yes→→ Why do you receive this service in another CSA? Circle all that apply.
B. No
C. Unknown
A. Positive relationship with previous provider.
B. Poor quality in CSA
C. Too far
D. Too much red tape
E. No transportation
F. Too ill to travel
G. Denied service in CSA
H. Other (please specify:_____)

56.)

Please rate the following items on a scale from 1 to 5: 1 being very good and 5 being very bad.					
	Very Good				Very Bad
The availability of the home health care service provider?	1	2	3	4	5
The quality of care you receive from the provider?	1	2	3	4	5

57.) How do you pay for this service?
A. Medi-Cal
B. Medicare
C. Ryan White
D. Private health insurance
E. Individual funds
F. Other (please specify:_____)
G. Unknown

(The preceding 7 questions will be repeated for the following services: hospice, buddy/companion, client advocacy, day or respite care, emergency financial assistance, housing assistance, food bank, home delivered meals, transportation, service outreach, permanency planning, and other services specified by the respondent.)

(B.) General Services

1.) Since moving to the current county of residence, have you (family member/care person) ever sought services in another county?

A. Yes→ → → Have you (they) been denied services in another county?

B. No
A. Yes→ → → Which services and in what county(s)?

C. Can't remember
B. No
Service(s)_____ County_____

C. Can't remember
Service(s)_____ County_____

2.) Do you (family member/care person) need any other services, not previously mentioned, that are not available to you (them)?

A. Yes→ → →What services are needed?_____

B. No

C. Unknown

3.) Whether or not services were available, what are your (their) top 5 needs as a person living with HIV/AIDS? (Your responses don't have to be ranked.)

1. _____
2. _____
3. _____
4. _____
5. _____

4.) Below is a list of factors. Please indicate whether or not you think it affects service delivery in your area by answering Y (yes), N (no), NA (not applicable), or UK (unknown). Please rank each factor that affects service delivery on a scale from 1-10, 10 being a great barrier to service delivery and one being a mild barrier to service delivery.

	Y/N/NA/UK	Rank
A. Physical geographic constraints (i.e., mountain ranges)		
B. Distance - services are too far		
C. Adequate facilities and staffing to provide services		
D. Lack of local funds, grants, etc.		
E. Service priority/allocation (needed services not highly prioritized or not funded i.e., return to work)		
F. Jurisdictional/political issues (county line creates barriers)		
G. Needs/issues of affected population		
H. Public health infrastructure constraints		
I. Turf Issues between service providers		
J. Other (please explain):_____		

The following statements refer to the <u>needs assessment administered through the consortium and to consortium meeting attendance</u>. Please indicate the degree to which you agree with the following:

II. NEEDS ASSESSMENT& CONSORTIUM/PLANNING COUNCIL INVOLVEMENT

	Service Delivery	Strongly Agree	Agree	Disagree	Strongly Disagree	Un-certain	N/A
	I have participated in a needs assessment in my current county of residence.	1	2	3	4	9	8
	I have participated in a needs assessment in my current county of residence within the last year.	1	2	3	4	9	8
	When completing the most recent needs assessment, I felt pressured to respond in a particular way.	1	2	3	4	9	8
	I am receiving services for needs I identified in the needs assessment.	1	2	3	4	9	8
	The consortium/planning council provided the results of the needs assessment to me.	1	2	3	4	9	8
	I have not had an opportunity to identify my individual needs to my local consortium/planning council.	1	2	3	4	9	8
	I feel very comfortable and confident relaying my needs to the consortium/ planning council through public comment.	1	2	3	4	9	8
	I feel very comfortable and confident relaying my needs to the consortium/ planning council through needs assessments.	1	2	3	4	9	8
	I would feel very uncomfortable relaying my needs to the consortium/planning council through a provider survey (interview).	1	2	3	4	9	8
	I feel that client focus groups are the best way of communicating my needs to the consortium/planning council.	1	2	3	4	9	8
	The consortium/planning council listens to my needs/concerns.	1	2	3	4	9	8
	I attend consortium/planning council meetings regularly (once a month).	1	2	3	4	9	8
	The consortium/planning council has improved my quality of life.	1	2	3	4	9	8

1.) In what situations might you (they) be most comfortable and confident in relaying your (their) individual needs to your (their) local planning body (consortium/planning council)?

_____

2.) How many meetings have you (they) attended in the last year?_____

3.) Which of the following best describes your (their) reason(s) for not attending? (Please circle all that apply.)

A. Unaware of the time
B. Unaware of the location
C. Meeting location was not accessible
D. Meeting time was not convenient
E. Too ill to attend
F. Poor meeting structure
G. Unproductive process
H. Other (please explain):_____
I. None of the above - I attend meetings regularly.

4.) In addition to being a client (care person), are you (please check all that apply):

A. Consortium/planning council member
B. Provider agency employee
C. Fiscal agent

III. DEMOGRAPHICS

1.) In what county do you (they) reside? _____

2.) How long have you (they) lived in this county?

A. <1 year
B. 1-2 years
C. 3-4 years
D. 5-6 years
E. 7+ years
F. Unknown

3.) What is your (their) gender?

A. Male
B. Female
C. Other (please specify)_____

4.) What is your (their) age group?

A. <13
B. 13-19
C. 20-30
D. 31-40
E. 41-50
F. 51-60
G. 61+

5.) What is your race/ethnicity?

A. White
B. Black
C. Asian/Pacific Islander
D. Aleutian/Eskimo/Native American
E. Other

6.) Are you of Hispanic origin?
A. Yes B. No

7.) What was your (their) approximate 1997 household income?
A. <$5,000
B. $5,001-$10,000
C. $10,001-$20,000
D. $20,001-$30,000
E. $30,001-$40,000
F. $40,001-50,000
G. $50,001+
H. Unknown

8A.) Do you have HIV disease?
A. Yes → → → If yes, are you:
B. No (Go to question 9.)
C. Unknown (Go to question 9.)
D. Rather not say (Go to question 9.)

A. HIV+, no symptoms (or very minor symptoms) (Go to 8B)
B. HIV+, symptoms, not AIDS (Go to 8B.)
C. AIDS (diagnosed) (Go to 8C.)
E. Unknown (Go to 8B.)
F. Other _____ (Go to 8B.)

8B.) If you have HIV disease, what year were you (they) diagnosed? _____(Go to 8D.)

8C.) In what year were you (they) diagnosed with AIDS?_____
IF YOU (THEY) HAVE BEEN DIAGNOSED WITH AIDS, do you (they) receive services in the county where you (they) were first diagnosed with AIDS?
A. Yes
B. No
C. Unknown

8D.) What experiences may have been responsible for your (their) exposure to HIV? (Circle all that apply.)
A. Sexual intimacy with a partner of the same sex
B. Sexual intimacy with a partner of the opposite sex
C. Birth to an infected parent
D. Use of intravenous drugs
E. Blood transfusion
F. Source of infection is unknown to me
G. Other (please explain): _____

9.) Do you (they) have any suggestions that might improve the current system of care?

_____

10.) **If respondent indicated they attended meetings (sec II, question 2)**: Since you have attended a consortia meeting in the last year, do you want to participate in the consortium/planning council survey?

A. Yes
B. No

****

This concludes the client survey. We appreciate your taking the time to call in to respond to our survey.
If you have any comments or concerns you can contact Denise Absher (916) 322-3150 or Dixie Chan (916) 322-4634 of the Office of AIDS.

As I mentioned, the results will be available in May of 1999! Please contact Denise or Dixie if you would like to receive a copy of the results.

THANK YOU FOR YOUR PARTICIPATION!!!!

CONSORTIA/PLANNING COUNCIL MEMBERS

AN EVALUATION OF CALIFORNIA'S CONSORTIA MODEL

SURVEY SCREENING

What is your relationship to Ryan White services or the clients receiving them? Are you:

→a Ryan White client receiving direct services? (If yes, client survey administered).

→a **family member**[1] of a Ryan White client?

If yes, is your family member or client able to call?

If yes, would you encourage them to call? (If yes, thank the caller for encouraging the client/family member to call, and ask the caller if1 they are receiving services (if yes, give client survey). If not receiving services, ask caller if they are familiar with their local consortium/planning council (if yes, give the consortium/planning council survey).

If no, are you calling to respond on behalf of a client who is receiving Ryan White services? If yes, would you respond to the interview based on your experiences as a family member? (If yes, shortened version of the client survey administered).

If caller is responding on behalf of client, client survey administered.
We would like you to respond on behalf of your family member. However, if you are receiving Ryan White services as well, you are welcome to work through the survey a second time based on your experiences as a Ryan White client.

→a **care giver**[2] of a Ryan White client?

If yes, is the client able to call?

If yes, would you encourage them to call? (If yes, thank the caller for encouraging the client to call, and ask the caller if they are familiar with their local consortium/planning council and if so the consortium/planning council survey will be administered).

If no, are you calling to respond on behalf of a client who is receiving Ryan

1 For the purpose of this study, a family member is defined as a spouse, relative, partner, close friend, or significant other caring for a Ryan White client with HIV disease. A family member may also be defined as a client who has not been diagnosed with HIV disease but is eligible to receive Ryan White services.

2 For the purpose of this study, a care giver is defined as a person who is employed to care for a Ryan White client with HIV disease.

White services? If yes, Would you respond to the interview based on your experiences as a care giver? (If yes, shortened version of the client survey administered).
If caller is responding on behalf of client, client survey administered.

→a consortium/planning council member, a provider, or a fiscal agent? If yes to any, ask: Are you also a client? If yes, client survey administered. If no, give consortium/planning council survey administered.

→If none of the above categories apply: what motivated you to call? (What is the purpose of your call?). Are you familiar with your local area consortium/planning council? Perhaps you would like to participate in the consortium/planning council survey.

Please be assured that no identifying information will connect you to your answers; your responses will be completely confidential.

Have you seen the flyer advertising this study? Would you like to hear a little bit about the study (if yes, give background) or would you prefer to begin the survey now?

The **client survey** consists of three parts:

I. Health Care Services
   A. Specific Services
   B. General Services
II. Needs Assessment/Consortium or Planning Council Involvement
III. Demographics

OR

The **consortium/planning council** survey consists of five parts:

I. Membership
II. Policies and Procedures
III. Needs Assessment
IV. Service Delivery
V. Demographics

I will take down all of your additional comments at the end of the survey. You might want to jot down notes to yourself as we go through the survey so that you don't forget to relay them to me. We anticipate the results of this study will be available by May of 1999.

THANK YOU FOR YOUR PARTICIPATION!!!

CONSORTIUM/PLANNING COUNCIL SURVEY

I. MEMBERSHIP

(1.) What county(ies) does your consortium/planning council serve?_____

(2.) How long have you lived in the area served by your consortium/planning council?

A. < 1 year
B. 1-5 years
C. 6-10 years
D. 11-20 years
E. 21+ years

(3.) Are you a member of the local consortium/planning council?

A. Yes
B. No (Go to question 5)

(4.) How long have you been a member of this local consortium/planning council?
A. < 1 year
B. 1-2 years
` C. 3-4 years
D. 5+ years

(5.) Have you ever been an officer of this area's (name) consortium/planning council?
A. Yes
B. No (Go to question 8)

(6.) Are you currently an officer or were you previously an officer?
A. Currently an officer
B. Previously an officer
C. Both

(7.) How many years, in total, have you served as an officer of your consortium/planning council?
A. <1 year
B. 1-2 years
C. 3-4 years
D. 5+ years
E. Unknown

(8.) Have you ever been a voting member of this area's (name) consortium/planning council?
A. Yes
B. No □ If a consortium member, have you applied to become a voting member?
A. Yes (Go to question 11)
B. No→ → → Why haven't you applied?
C. Unknown (Go to question 11)
A. I am not interested
B. I don't have time
C. I don't attend regularly
D. Other: _____
(Go to question 11)

(9.) Are you currently a voting member?
A. Currently a voting member
B. Previously a voting member
C. Both

(10.) How many years, in total, have you served as a voting member of your consortium/planning council?
A. <1 year
B. 1-2 years
C. 3-5 years
D. 6+ years
E. Unknown

(11.) On average, how many times have you attended a consortium/planning council meeting in the last year (not including committee work)?

A. 0 times
B. 1-2 times
C. 3-4 times
D. 5-6 times
E. 7-8 times
F. 9+ times
G. Unknown

(12.) How long have you been attending consortium/planning council meetings?

A. <1 year
B. 1-2 years
C. 3-4 years
D. 5+ years
E. Unknown

(13.) Have you ever served as an officer or voting member on a Ryan White consortium/planning council in another area?

A. Yes
B. No (Go to question 16)
C. Can't Remember (Go to question 16)

(14.) In which other counties did you serve as an officer or voting member of a Ryan White consortium/planning council?_____

(15.) How satisfied were you with the consortium/planning council's operation? Please list the rating for each consortium/planning council on which you served.

County_____	County_____
□ 1. Very satisfied	□ 1. Very satisfied
□ 2. Moderately satisfied	□ 2. Moderately satisfied
□ 3. A little unsatisfied	□ 3. A little unsatisfied
□ 4. Very unsatisfied	□ 4. Very unsatisfied
□ 5. Unknown	□ 5. Unknown

NOTE: The remaining questions refer to current consortium/planing council experience.

(16.) How long have you been involved in the activities of the consortium/planning council serving the HIV/AIDS community?

A. <1 year
B. 1-2 years
C. 3-4 years
D. 5+ years
E. Unknown

(17.) Why are you involved in the activities of the consortium/planning council? (Please circle all that apply.)

A. Participation is part of my job
B. I have a friend/family member with HIV
C. I have HIV/AIDS
D. I am an interested community member
E. Other (please explain)_____

(18.) How did you originally hear about the consortium/planning council?

A. From a co-worker
B. From a friend
C. Through a newspaper/newsletter
D. Case Manager/Social Worker
E. AIDS Service Organization
F. State Office of AIDS (Department of Health Services)
G. Other (please explain)_____

II. POLICIES AND PROCEDURES

(1.) Have you ever received any of the following documents from your consortium/planning council? (Please circle all that apply.)

A. Consortium/Planning Council Policies and Procedures Manual
B. Planning Council By-Laws **(PC ONLY)**
C. Consortium/Planning Council Meeting Minutes
D. Committee Meeting Minutes
E. Consortium/Planning Council Needs Assessment Results
F. Consortium/Planning Council Service Plan
G. Conflict of Interest
H. Reports from service providers (i.e., number of clients served, services provided...)
I. Consortium/Planning Council application to the State Office of AIDS
J. Other (please list)_____

(2.) Has your consortium/planning council established any committees?

A. Yes
B. No (Please go to page 7)
C. Unknown (Please go to page 7)

(3.) Are you required to participate on a committee as part of your membership?

A. Yes
B. No
C. Unknown

(4.) What types of committees does your consortium/planning council have? (Please circle all that apply)

A. Executive (usually officers and committee chairs)
B. Needs Assessment
C. Membership
D. Persons Living with HIV/AIDS
E. Quality Assurance
F. Specific County Sub-Committees (multi-county consortia)
G. Finance/allocation
H. Other (please list):_____
I. Unknown

The following refer to consortium/planning council policies and procedures. Please rate your understanding of the following items:

Policies and Procedures	Excellent	Good	Fair	Poor	Uncertain
The consortium/planning council policies	1	2	3	4	9
The consortium/planning council procedures	1	2	3	4	9
Basic operational structure (by-laws, operating procedures, decision making processes) of the consortium/planning council	1	2	3	4	9
The consortium/planning council's mission	1	2	3	4	9
How the consortium/planning council's mission is to be accomplished	1	2	3	4	9
The consortium/planning council's formal definition of conflict of interest	1	2	3	4	9
The plan developed by the consortium/planning council to manage conflict of interest	1	2	3	4	9
The consortium/planning council's procedures for addressing grievances	1	2	3	4	9

The following statements are about consortium/planning council policies and procedures. Please indicate the extent to which you agree with these statements.

Policies and Procedures	Strongly Agree	Agree	Disagree	Strongly Disagree	Uncertain
The consortium/planning council has not had to use any procedures for addressing grievances.	1	2	3	4	9
When used, the procedures for addressing grievances are usually effective.	1	2	3	4	9
The consortium/planning council has established many committees.	1	2	3	4	9
Most of the consortium/planning council's actions are driven by committee recommendations.	1	2	3	4	9
The consortium/planning council provides for public comment at its regular meetings.	1	2	3	4	9
People usually show up for public comment at meetings.	1	2	3	4	9
The consortium/planning council rarely responds to specific complaints presented during public comment.	1	2	3	4	9
The consortium/planning council carefully reviews current epidemiological data, i.e., number of reported AIDS cases in the county by gender, age, race, ethnicity, exposure category etc.	1	2	3	4	9
Epidemiological data is reviewed at least once a quarter.	1	2	3	4	9
The consortium/planning council conducts annual self-evaluations.	1	2	3	4	9
Overall, the consortium/planning council's operating principles are unfair.	1	2	3	4	9
The consortium/planning council is able to work through various opinions brought to the table.	1	2	3	4	9
The consortium/planning council does not accomplish its goals.	1	2	3	4	9

III. NEEDS ASSESSMENT

(1.) Has the consortium/planning council conducted a needs assessment in the past year?

A. Yes
B. No (Please go to question 7).
C. Unknown (Please go to question 7).

(2.) Who conducted the needs assessment?

A. Contracted out (i.e. someone else did it completely)
B. Contracted out with the help of consortia/planning council members
C. Utilized technical assistance pool through the Office of AIDS
D. Conducted by consortium/planning council members
E. Other (please specify):_____
F. Unknown

(3.) Were there any difficulties encountered in performing the needs assessment?

A. Yes → → What difficulties were encountered? (Please circle all that apply)
B. No
C. Unknown

A. Lack of expertise
B. Lack of funds
C. Difficulty in reaching clients
D. Difficulty in reaching infected community members/potential clients (those who aren't already clients)
E. Providers don't cooperate
F. Lack of participation/responses
G. Unknown
H. Other (please specify):_____

(4.) Were you given the results of the last needs assessment?

A. Yes
B. No (Please go to question 7).
C. Unknown (Please go to question 7).

(5.) Did the needs assessment identify any specific populations with special needs?

A. Yes
B. No (Please go to question 7).
C. Unknown (Please go to question 7).

(6.) What populations were identified?

A. Women
B. Infants/Children
C. Homeless
D. Substance Users
E. Native Americans
F. Hispanics
G. Asian/Pacific Islanders
H. African Americans
I. Other (please specify_____)

(7.) What would you identify as the top 5 needs of persons living with HIV/AIDS (PLWAs) in your

consortium/planning council's service area? (Your responses don't have to be ranked.)

1. _____
2. _____
3. _____
4. _____
5. _____

Below is a list of special populations. Please indicate how well you feel their needs are being met in your service area. If you do not feel the population is in your service area, please indicate "not applicable".

Special Populations	Well Met	Adequately Met	Somewhat Met	Not Met	Uncertain	Not Applicable
Pregnant Women	1	2	3	4	9	8
Women	1	2	3	4	9	8
Homeless	1	2	3	4	9	8
Substance Users	1	2	3	4	9	8
Native Americans	1	2	3	4	9	8
Hispanics	1	2	3	4	9	8
Asian/Pacific Islanders	1	2	3	4	9	8
African Americans	1	2	3	4	9	8
Infants/Children	1	2	3	4	9	8
Gay men of color	1	2	3	4	9	8
Young men having sex with men	1	2	3	4	9	8
Transgender	1	2	3	4	9	8

Please go to next page.

IV. SERVICE DELIVERY

The following refer to the <u>procedures used for the delivery of services in your service area</u>. Please indicate the degree to which you agree with the following:

Service Delivery	Strongly Agree	Agree	Disagree	Strongly Disagree	Uncertain	Not Applicable
I am familiar with the procedures used for setting service priorities.	1	2	3	4	9	8
I am satisfied with the procedures for setting service priorities.	1	2	3	4	9	8
The consortium/planning council does a resource inventory (i.e., checks for other available resources in the community) before deciding which services are to be funded.	1	2	3	4	9	8
Funding decisions are usually based on service needs.	1	2	3	4	9	8
The consortium/planning council never provides an explanation/justification of funding decisions when they are not based on service needs.	1	2	3	4	9	8
I am very dissatisfied with the process the consortium/planning council uses to make funding decisions, i.e., which service providers will be funded.	1	2	3	4	9	8
The fiscal agent uses fair and impartial processes when determining which service providers are to be funded.	1	2	3	4	9	8
The fiscal agent does not divide funds equitably when allocating funds to contracted service providers.	1	2	3	4	9	8
The current system of care adequately delivers needed services to persons living with HIV in my service area.	1	2	3	4	9	8
Service delivery is flexible in my service area, i.e., service categories can change to meet changing needs of the served populations.	1	2	3	4	9	8

(1.) When was the last time the consortium/planning council evaluated the service providers to ensure quality?

A. Within the current fiscal year (April 1, 1997-March 31, 1998)
B. Last year (1996-97)
C. Two years ago (1995-96)
D. Three years ago (1994-95)
E. Never
F. On as ongoing basis
G. Other (please explain)_____
H. Unknown

(2.) Who participates in the service provider evaluations?

A. The fiscal agent
B. The fiscal agent and consortia/planning council members
C. As outside organization
D. Other (please specify)_____
E. Unknown
F. Not Applicable

(3.) Below is a list of factors. Please indicate whether or not you think it affects service delivery in your area by answering Y (yes), N (no), NA (not applicable), or UK (unknown). Please score each factor that affects service delivery on a scale from 1-10, 10 being a great barrier to service delivery and one being a mild barrier to service delivery.

	Y/N/NA/UK	Rank
A. Physical geographic constraints (i.e., mountain ranges)		
B. Distance - services are too far		
C. Adequate facilities and staffing to provide services		
D. Lack of local funds, grants, etc.		
E. Service priority/allocation (needed services not highly prioritized or not funded i.e., return to work)		
F. Jurisdictional/political issues (county line creates barriers)		
G. Needs/issues of affected population		
H. Public health infrastructure constraints		
I. Turf Issues between service providers		
J. Other (please explain):_____		

(4.) Do you have any suggestions for improving the consortium/planning council process and/or suggestions for improving service delivery in your community?

_____
_____

_____

_____
_____
_____

V. DEMOGRAPHICS

(1.) Are you currently affiliated with a provider agency?

A. Yes
B. No (Please go to question 9)

(2.) Are you (circle all that apply):

A. An employee
B. A volunteer
C. A member of the board of directors
D. Other (Please specify:_____)

(3.) What type of provider agency?

A. Hospital or hospital-based clinic
B. Public-funded community health center
C. Public-funded community mental health center
D. Other community-based service organizations (including private/non-profit)
E. Persons with AIDS (PWA) coalition
F. Health department
G. Other public agency
H. Solo/group private health practice
I. Other (please specify)_____
J. Unknown

(4.) What is your time base, i.e., full-time, part-time?

A. Full-time
B. ½ time
C. 3/4 time
D. Other (please explain):_____

(5.) What is your title? Please choose the title that best describes your primary responsibility.

A. Director
B. Assistant Director
C. Manager
D. Case Manager/counselor
E. Doctor
F. Nurse (licensed)
G. Secretary/clerical
H. Fiscal Agent
I. Unlicensed care provider (nursing assistant, non-licensed home health care...)
J. Other (please explain):_____

(6.) Approximately how many clients has your agency served in the last 12 months?

_____Number of clients served in all programs
_____Number of HIV+ clients
_____Number of clients receiving Title II funded services

(7.) Is your agency currently being funded with Ryan White dollars?

A. Yes
B. No → → Have you ever received Title I or Title II funds?
C. Unknown

A. Yes
B. No
C. Unknown

(8.) The table below presents a list of possible HIV/AIDS funding sources. Please indicate if your agency receives revenue from the funding source. If it does, please indicate how critical each funding source is to your agency by ranking it on a scale from 1-10, 1 being not critical at all and 10 being very critical.

Funding Source	Does agency receive funds from this source? Please indicate Y (yes), N (no), or UK (unknown)	How critical is the funding source? 1=not critical at all, 10=very critical
RYAN WHITE: Title I	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Title II	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Title III	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Title IV	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Special Projects of Nat'l Significance (SPNS)	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Other Sources:		
State Medicaid Program (fee for service)	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
State Medicaid Program (managed care i.e., HMO, PPO, or other capitation)	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Private Insurance (fee for service)	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Private Insurance (HMO, PPO, or other capitated methods)	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Self-pay	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Other State public funds	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Other Federal funds	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Gifts/donations	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Grants	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**
Other (please explain)_____	**Y N UK**	**1 2 3 4 5 6 7 8 9 10**

(9.) Have you accessed any Ryan White eligible services in the last year?

A. Yes → → → At end of survey ask if interested in participating in the client survey?
B. No
C. Unknown

(10.) What is your gender?
A. Male
B. Female
C. Other (please specify)_____

(11.) What is your age group?
A. <13
B. 13-19
C. 20-34
D. 35-44
E. 45-54
F. 55-64
G. 65+
H. Rather not answer

(12.) What is your race/ethnicity?
A. White
B. Black
C. Asian/Pacific Islander
D. Aleutian/Eskimo/Native American
E. Other

(13.) Are you of Hispanic origin?
A. Yes B. No

(14.) What was your 1997 household income?
A. <$5,000
B. $5,001-$10,000
C. $10,001-$20,000
D. $20,001-$30,000
E. $30,001-$40,000
F. $40,001-50,000
G. $50,001+
H. Rather not answer

****

This concludes the consortium/planning council survey. We appreciate your taking the time to call in to respond to our survey. If you have any comments or concerns you can contact Denise Absher (916) 322-3150 or Dixie Chan (916) 322-4634 of the Office of AIDS.

As I mentioned, the results will be available in May of 1999! Please contact Denise or Dixie if you would like to receive a copy of the results. THANK YOU FOR YOUR PARTICIPATION!!!!

ATTENTION

The State Office of AIDS wants to hear from you!!!!

We need your help in evaluating AIDS services and/or your local consortium/planning council.

Please call our toll-free number 1-800-311-4905 to participate in the survey.
The first 300 callers will receive a 10-minute phone card!!!!

CALL

1-800-311-4905

Phone bank hours and days:

Tuesday-Friday 4:00 p.m.- 9:00 p.m.
Saturday 11:00 a.m. - 4:00 p.m.

October 10 – 31, 1998

This opportunity to be heard is only for three weeks.

Completely Confidential

Se Habla Espanol.

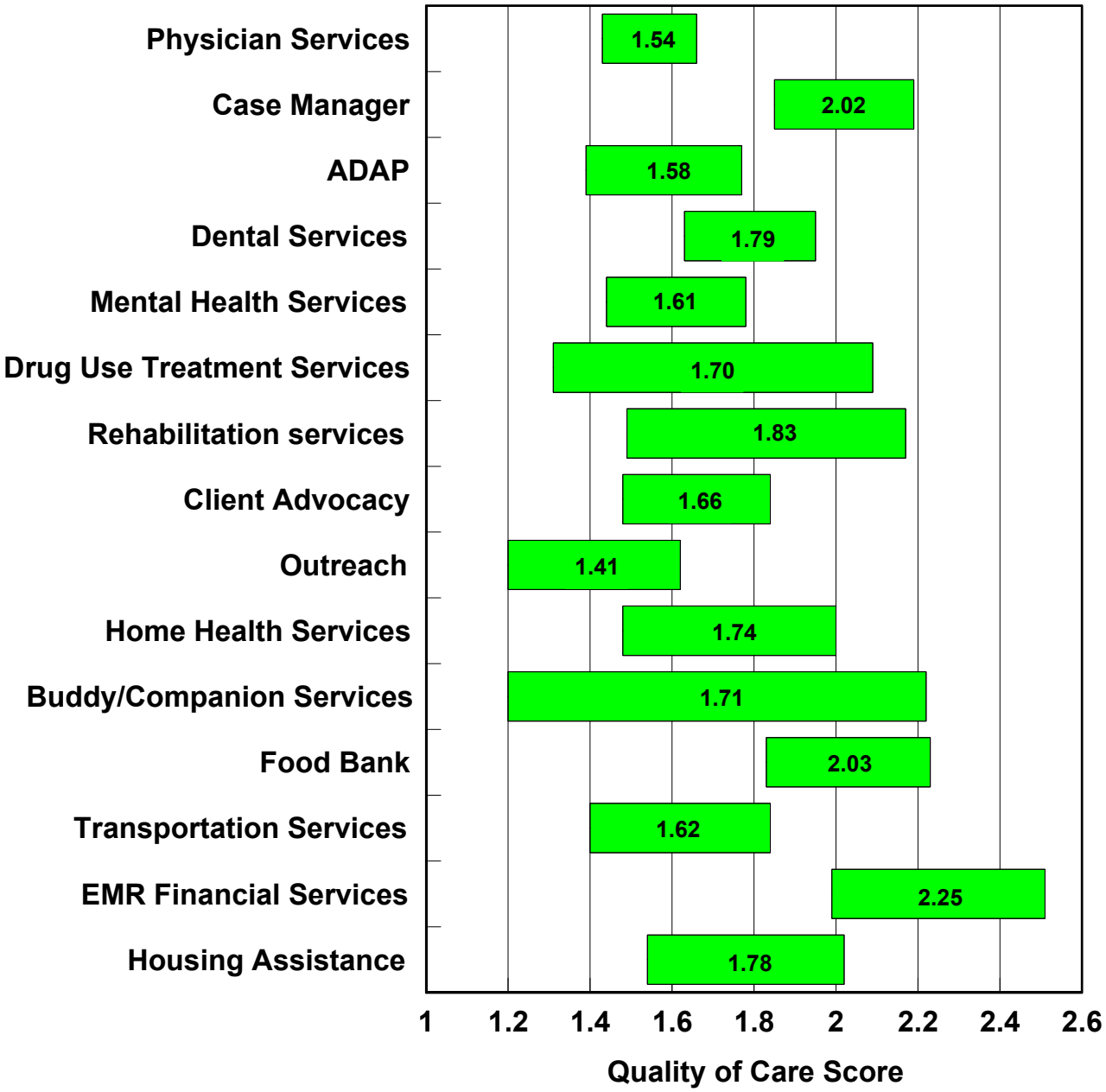
Free 10 Minute Phone Card to First 300 Callers.

Tell Us How You Feel About AIDS Services.

THANK YOU FOR YOUR PARTICIPATION!!!!!!!

The California Department of Health Services Office of AIDS (OA) is conducting this study in conjunction with the Federal Department of Health and Human Services, Health Resources and Services Administration (RFQ# 240-OA-35(7)ABG). The OA has contracted with California State University Sacramento, Institute for Social Research to establish the telephone bank and collect the data for this project. Your responses will be COMPLETELY confidential.

95% Confidence Limits by RWCA Services



Numbers within bars are the mean values calculated by the following scale: "Very Good"=1, "Good"=2, "Average"=3, "Inadequate"=4, "Very Bad"=5

Respondent Feedback

1. Provide more services for people who are getting out of prison.
2. Treat and help as many people as the system can support.
3. Would like for the doctors to be more compassionate. Especially when dealing with a patient's prognosis.
4. Would like more information on the RWCA in an easy to understand format.
5. The government needs to pressure pharmaceutical companies to lower their costs and to develop a vaccine to prevent new infection.
6. The public needs to be better informed via pamphlets, etc., especially IV drug users and people who are promiscuous. Also the need for a healthy diet should be publicized as a means of keeping HIV at bay.
7. More funding is the first and foremost thing. The case manager is overloaded and too busy to respond.
8. Need to rectify the turf issues between service providers. Some clients take advantage and receive duplicative services from different providers.
9. Would like to see less politics between the providers.
10. Some oversight needs to be present in local area. Clinics should be checked on by the state.
11. Make sure that safe sex is emphasized in prevention counseling.
12. Need more money for food, transportation, housing, and training (getting back to work). Of these items training is the most important.
13. Need better referrals to doctors and dentists. Need more access to medications. A lot of waste goes on in the county system. I have been renting a wheel chair with county money when it would have been cheaper to just buy the wheel chair and I could return it to the county when it is no longer needed.
14. In my county case management is poor. They are difficult to contact, and they give you the third degree when you ask for help. We need a reliable way to contact them. Their inaccessibility makes all of my services difficult to acquire.
15. Better outreach for people and more public awareness needed about available services. Need to publicize availability of services through media ads. Speakers should go to local health/nutrition classes and let people know that services are available. We need public awareness days for AIDS to publicize issues related to HIV/AIDS patients.
16. More centralization. Ability to compensate people. More transportation.
17. Better outreach. Identify those who are HIV positive and offer them the services.
18. Need to educate people to be more respectful of others and their lifestyles.
19. We need a new consortium inter-county affiliation.
20. There should just be one building for services to ensure confidentiality and prompt care.
21. Better follow-up with clients, better callbacks. Be pro-active in pursuing the clients.
22. Would like to see less politics between the providers and more advocacy for the clients.
23. There should be increased funding for all of the services we discussed. Faster FDA approval of drugs issued through ADAP. Vocational training for people who are able to return to work.
24. Bring more clients into the consortium; get a food bank; better section 8 (HUD), better transportation.
25. Service providers should be more thoroughly trained and knowledgeable; need employee education and more coordination between services; clients are tired of getting different answers from different people.

26. More staff and money needed. Other than that they do a great job.
27. Quit worrying about what the republicans want and what looks good and worry about what is needed. Act more like a human rather than a beaurocrat!
28. Glyco supplemental to boost one's immune system. It has been researched and the products work. It could cut down on hospital stays and people would not be dying.
29. More money.
30. Find a cure.
31. In my consortium all services are provided from one agency and so there are no turf issues. Managed care can be wonderful if done right, the way it is done in some areas everyone is fighting over who gets to claim that person as a client.
32. Just because a patient forgets about going to the doctor it shouldn't mean that she can't see that doctor anymore.
33. Better medicine. Quality of medicines has been improving.
34. Job assistance needed and jobs needed by employers.
35. More financial assistance needed.
36. Much more compassion please. Also, clients need to know the amount of money allocated for each client. Need to know what is allowed for usage. Housing use, much more focus needed on women and children in the area.
37. Financial counseling and case management needed.
38. Monthly focus groups needed.
39. Wish that more could be done at home rather than having to go into places to make changes due to changes in my status.
40. Going on to social security after diagnosis was hard, because this made it difficult to qualify for benefits from work.
41. Withhold what funds the system doesn't use and distribute the following year. Make sure all consortiums use the same programs and distribute the same items that are needed.
42. Educate the infected population.
43. Hire more people for personal care. Educate the population so they know what they are doing. More care and concern for people individually.
44. Need someone to listen to the needs of people. They don't listen to people enough. Too much trouble to get help.
45. Need to communicate better to their clients and the public.
46. Lack of funds a problem.
47. There needs to be clinics from the large hospitals closer to my county. I travel too far to get services. Buddy/companion services should be available. Mental health is hard to get.
48. Make applying for services by agency easier so small agencies can get involved. A functioning committee run by PLWH to give input to the council. Mandate that all providers record and send to planning council and fiscal agent the board of directors and staff located in the communities that are being served.
49. Lack of transportation provided by caregivers or consortium. The consortium does not have enough funds to keep people employed.
50. More knowledge and client participation in the consortium process.
51. My county needs more money. We need more services such as food banks, real case managers, more people to staff offices. There are no support groups for HIV+ people and they are needed. Home health care is needed. Should be able to see specialist when needed. I don't like having HIV.

52. Multiple warring factions creating a non-cooperative group with redundant care. Roles are wasteful of money and resources and do not have proper planning and management. Better case management is a top priority. We need more efficient allocation of funds.
53. Educate more healthcare givers regarding how HIV is spread so they don't insult people with HIV. In other words the wearing of masks and gloves when taking a pulse.
54. Better transportation services are needed.
55. Need more case managers, they are over burdened. Need more funds for the very sick people and also more education regarding the fact that not just the traditional population is at risk but all people are.
56. Need more doctors and support groups.
57. Eligibility standards should be based on need not just income. I am denied services.
58. Education for the community is needed. Also for workers in the field. More providers are needed. They are scarce in my county. Also there is a lack of funds.
59. Clients get confused at the consortia meetings. Lots of friction there that's why people don't want to go.
60. Services in the area are excellent. Outreach needs more attention. Housing options need improvement for low income or for someone who is ill.
61. Financial help for paying utilities and household needs is required.
62. I wish there were more doctors who could help with HIV/AIDS for low or no income people. There is a need to ensure medications are available. I feel the ADAP program is good.
63. We need to have both a nurse and HIV case manager. They both need expertise. An HIV client who is on SSI should be allowed food stamps or other food assistance. Transportation services should be more accessible. HIV client accessibility to section 8 is needed and more funding for benefits.
64. The food bank should provide more in the way of healthful food i.e., more meat and milk. Also we need more detergent and a place to go where HIV patients can afford to do their laundry.
65. Make sure that services are still made available. Without ADAP some people can't afford their medications. Also they need help with housing, food, medical care, and medications. These should be provided.
66. Take the government and red tape away and put in people that have some involvement. Paying more people to allocate the money wastes the money. Also mental health needs more attention. We need counselors who have knowledge of the disease.
67. There is a need for alternative medicine. We need to know how important they are in conjunction with conventional medicine. Doesn't like the sex survey that is required for services. Resents being treated like a person who is irresponsible. Not a stereotype.
68. Needs assessment should be done more than once a year. An outside agency should work in the council and make an impact.
69. There should be more help for people in the rural areas. Lack of transportation is a problem.
70. Better medical care is needed. It should be more individualized care for PLWH.
71. Need to show the public the people who are really sick. Not always the healthy HIV patients.
72. County hospital environment is substandard. Dirty, run down, bugs, etc.

73. A major hurdle to getting care is inability of MCAP to provide what they say they will.
74. More leniency in guidelines for receiving services is needed. More money is also needed.
75. More funding for county medical programs relating specifically to HIV is needed. Also more money should be allocated to finding qualified case managers because they're way overloaded.
76. We need to have a single payer source, as in what Clinton was proposing. Care is being driven by economics not by need.
77. Small counties should have more specialized doctors.
78. We need to start out a little earlier on youngsters to get them to understand that you aren't going to die right away. Also I need help with my insurance.
79. Staff is overworked, meetings are awful. I drove an hour to talk about people who would get upset with things the consortia decided to do. I don't care if someone gets upset. I just need a closer doctor. Right now I have to drive 2 ½ hours for my doctor appointments.
80. More compassion from everyone is needed. Also more understanding and less me me me. Also we need to find a cure not another protease inhibitor. I've been on so many and they make you feel very sick and some people can't tolerate them.
81. Everyone needs more education and awareness. We need a needle exchange program.
82. The consortium should be more of a watch dog type of group that looks at agencies hard. When agency heads are consortia members they are all best buddies and friends and there is no one to complain to. I call OA to make a grievance, people are afraid of retribution or being disenfranchised.
83. More money into the community is needed. Also more awareness of the situation and how the disease is spread.
84. All agencies can't become complacent. They have to fight constantly. There are so many people who fall between the cracks and there are people who no agency can help because of certain circumstances.
85. We need more information out there. We should get young kids educated. Could use better publicity especially the last few years. They've gone to other diseases and this disease is still killing people. Need to take care of us.
86. Having staff that really understands what this disease is like is important. There should be a needs assessment done yearly because things change so often.
87. More case managers are needed. There needs to be some confidentiality with the people about their private business.
88. In the large counties we need more programs that are culturally sensitive. Most Latinos who were getting infected did not know that services were available.
89. The people I take care of need help with secondary in home care, getting medical supplies, financial and legal assistance.
90. People need more meetings to attend to learn about this disease.